

# How Much Should a Research Participant Know?

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Research involves performing tests on animal subjects and sometimes even on human subjects. However, there are times researchers do not follow the ethical practices associated with the human subjects. This includes the extent of information related to the research that is [disclosed to the human subjects](#). Let us learn more about the ethical practices associated with research participants.

## Ethical Issues Raised by HeLa Cell Line

Research involving human subjects should depend on ethical and mutually productive agreements. The controversial example of HeLa cell lines highlights the importance of scientific transparency and participant consent.

The HeLa cell line was established in 1951 from cervical cells taken from an African-American female patient, Henrietta Lacks (HeLa). The cells showed robust growth and unrestricted distribution. This cell line to be the first successfully [immortalized human-derived cells](#) in the lab. The HeLa cell line made significant strides in basic research-based scientific discovery for decades. In fact, [more than 74,000 PubMed abstracts](#) published in 2013 alone included the use of HeLa cell line. Decades of research on the cell line enabled the development of a polio vaccine and the discovery of human telomerase.

However, according to recent controversy, Henrietta Lacks had not agreed to the scale of research. Three decades later the Lacks family were [provided an explanation on the role of HeLa cell lines](#) in basic science. Scientists are keen to change this landscape with ethical human participation and scientific research transparency.

## Disclosing Scientific Outcomes to Human Research Participants

The new paradigm established by the National Academies of Science, Engineering and Medicine (NASEM) calls for data sharing with research participants. Returning research results to voluntary participants can be engaging, ethical and respectful to those oblivious of their scientific contributions. Although not the norm, the emphasis on greater transparency in human participant-based research has become apparent considering the HeLa controversy. The new report recommends that regulators and policy-makers [revise the guidelines](#) with respect to the interests of research participants. The report available online includes strategies to discuss the process of returning individual-specific research results generated in research laboratories.

## Ethics of Sharing Research Information

According to the NASEM authors of the published report, returning expanded results must be [conducted on a 'cautious basis.'](#) Traditionally results were returned contingent to data with 'actionable' potential; however long-term significance is likely to improve during further research. Although it is now important to provide results and receive consent for further work, this relies on whether people want them. We must ask the voluntary participants in clinical research if they would like further information on their specimen then comply with their answer.

Advancements in scientific research depend on ethical partnerships, for potentially significant medical breakthroughs, while respecting patients and their families. Providing medical research data back to the contributors is also a broader push to establish further research participation. Giving a voice in research to those contributing their own tissue, cells and DNA can amplify their role in science. However, the ethics surrounding the topic are murky and surrounded by inconsistent regulations. US agencies continue to augment views on the matter.

## Regulating Research Transparency

The topic of ethical and consent-driven work recaps the importance of transparency and reproducibility in scientific research. The ability to [replicate novel findings](#) in previous studies can heavily influence progress in scientific research. Publishing negative results and disclosing errors help maintain scientific transparency. Permitting research transparency in this way can benefit scientists already in the field and those working to contribute to it.

Recent developments in medical research also highlight the aspect of scientific transparency in healthcare. This includes the first marijuana-based drug Epidiolex. Significant research breakthroughs from the bench to the clinic such as this take place only through meticulous and transparent scientific research. Basic research can [accelerate the medical landscape](#) through the development and optimization of therapeutics. Scientific research with human participants depends on reproducibility, volunteers and consent-based research continuation for a blend of ethics and transparency.

How much should a research participant know? Please share your thoughts with us in the comments section below.

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